

**ANXIETY, BURDEN AND DEPRESSION IN INFORMAL
CAREGIVERS OF TERMINALLY ILL (ORGAN
FAILURE) PATIENTS**

THESIS

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بِسْمِ اللَّهِ الرَّحْمَنِ الرَّحِيمِ

{ وَمَا أُوتِيتُمْ مِّنَ الْعِلْمِ إِلَّا قَلِيلًا }

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ABSTRACT

Objective: The aim of this study was to describe the characteristics of the informal caregivers of terminally ill (hepatic, cardiac, renal failure) patients and their care recipients; and to investigate the relationship between depression, anxiety and burden among informal caregivers.

Methodology: It was a cross-sectional study. Caregivers of terminally ill (hepatic, cardiac, renal failure) patients were recruited from the inpatient Internal Medicine departments, Kasr Alaini Faculty of Medicine. The Caregiver Questionnaire, Hamilton Anxiety and Depression Rating Scales, and the Modified Caregiver Strain Index were used.

Findings: Most of the caregivers experienced high levels of burden, severe anxiety and mild depression. Several factors showed a statistically significant correlation with caregiver burden, anxiety and depression including the care recipient's functional status, personality changes, mental functioning, presence of comorbidities, the Palliative Prognostic Score, being the main caregiver, duration of care giving, the caregiver's employment status, perceived health and impact on social activities. Caregiver burden, anxiety and depression were significantly correlated.

Key words: Caregiver - Informal caregivers - Terminal illness- Advanced organ failure

LIST OF ABBREVIATIONS

- **AD** Alzheimer's Disease
- **ADLs** Activities Of Daily Living
- **AHA** American Heart Association
- **AIDs** Acquired Immune Deficiency Syndrome
- **CAD** Coronary Artery Disease
- **CG** Caregiver
- **CHF** Congestive Heart Failure
- **CI** Confidence Interval
- **CKD** Chronic Kidney Disease
- **COPD** Chronic Obstructive Pulmonary Disease
- **COPE study** Creativity, Optimism, Planning And Expert Information Study
- **CPS** Clinical Prediction Of Survival
- **CR** Care Recipient
- **CRA** Caregiver Reaction Assessment

- **CVA** Cerebrovascular Accidents
- **DM** Diabetes Mellitus
- **DSM-IV** Diagnostic And Statistical Manual Of Mental Disorders 4th Edition
- **ESRD** End-Stage Renal Disease
- **GAD** Generalized Anxiety Disorder
- **GI** Gastro-Intestinal
- **Ham-A** Hamilton Anxiety Rating Scale
- **HAM-D** Hamilton Depression Rating Scale
- **HCC** Hepatocellular Carcinoma
- **HDRS** Hamilton Depression Rating Scale
- **HF** Heart Failure
- **HPS** Hepatopulmonary Syndrome
- **HRS** Hepatorenal Syndrome
- **HRSD** Hamilton Rating Scale For Depression
- **IADLs** Instrumental Activities Of Daily Living
- **IDU** Injection Drug Use
- **KPS** Karnofsky Performance Scale

- **MI** Myocardial Infarction
- **NFLD** Non-Alcoholic Fatty Liver Disease
- **NYHA** New York Heart Association
- **OR** Odds Ratio
- **P** P Value
- **RR** Relative Risk
- **RRT** Renal Replacement Therapy
- **USRDS** U.S. Renal Data System
- **WHO** World Health Organization

LIST OF IMPORTANT DEFINITIONS

TERMINAL ILLNESS

An individual is considered to be terminally ill if the medical prognosis is that the individual's life expectancy is six months or less if the illness runs its normal course. (*Medicare Benefit Policy Manual, 2004*)

PALLIATIVE CARE

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care: (*WHO, 2002*)

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;

- offers a support system to help the family cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

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ATTACHED DOCUMENTS

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| 5. | Modified Caregiver Strain Index |
| 6. | Palliative Prognostic Score |

INTRODUCTION

An individual is considered to be terminally ill if the medical prognosis is that the individual's life expectancy is six months or less if the illness runs its normal course. (*Medicare Benefit Policy Manual, 2004*)

Informal or family caregivers are unpaid friends or family members who “provide, arrange or oversee needed services because of functional disabilities or health needs”. (*Gaugler et al., 2003*)

Today, changes in the health care delivery system, including shorter hospital stays, have led to a shift in the cost and responsibility for the care of loved ones from health care providers to family caregivers. (*Levine, 1998; Guberman et al., 2001*) Family caregivers now require a greater capacity to understand health and medical information; seek out and use the patchwork of community resources; and navigate the increasingly complex, fragmented and costly health care and home and community-based service system. (*Feinberg, 2001*)

In day-to-day practice, family physicians are likely to see patients who serve as caregivers. In fact, one study of patients in a family practice demonstrated that 21 percent of the patients had caregiving responsibilities for persons with chronic medical conditions. (*Andolsek et al., 1988*)

The caregiver role can be stressful, and identifying these patients can give the family physician opportunities to help patients cope with the challenges of the caregiver role. Family physicians have a systematic

approach for assessing the degree of caregiver burden in these patients. Because caregivers are at increased risk for depression and anxiety, screening should be done to exclude the presence of either disorder. If there are problems, family physicians should provide practical counseling about common caregiving stresses and about resources that benefit caregivers. Helping the caregiver learn strategies for coping with difficulties may help reduce some of the stress the caregiver is experiencing. (*Parks & Noveilli, 2000*)

Research has uncovered the enormous physiological, psychological, and financial costs associated with informal care giving. Informal caregivers have increased stress and depression, (*Clyburn et al., 2000; Pinquart & Sorenson, 2003a*) worsened social and family life, (*Cameron et al., 2002*) physical illness (*Vitaliano et al., 2003*), increased feelings of burden (*Dunkin & Anderson-Hanley, 1998*) and decreased quality of life. (*Rees et al., 2001; Argimon et al., 2004*) Informal caregivers have been shown to be less likely to be employed and more likely to miss days of work and to quit or to retire early. (*Levine et al., 2000; Ho et al., 2005*) Equally important, the emotional and physical health of family caregivers has been shown to correlate with the health and successful rehabilitation of those with chronic illness. (*Han & Haley, 1999*)

Across more than 20 studies published in the past decade, there was consistent evidence that caregiving placed family members at risk for depression. (*Mittleman et al., 1995; Zanetti et al., 1996; Buckwalter et al., 1999; Deimling et al., 2001*) In fact, caregivers had higher rates of depression than the general population. (*Jackson & Cleary, 1995*) Multiple studies have shown that the incidence of depression in

caregivers is high, ranging from 18 to 47 percent, and caregivers who are depressed experience higher degrees of burden. (*Lawton et al., 1991*)

Caregiver burden, which is the negative impact of caregiving on the caregiver's life, has been associated with depressive symptoms (*Wight, 2000; Land et al., 2003*) and suicidal ideation. (*Rosengard & Folkman, 1997*) The consequences of a high caregiver burden include an increased risk of the need to place the family member in a long-term care facility as well as increased use of formal in-home services. (*Brown et al., 1990*) The societal and economic benefits of reducing the amount of caregiver burden are evident. (*Livingston et al., 1996*)

Clearly, family caregivers provide a substantial amount of free labor that undergirds the entire health care system. (*Arno et al., 1999*)

AIM OF WORK

- To identify the characteristics of the informal caregivers of terminally ill (hepatic, cardiac, renal failure) patients and their care recipients
- To investigate the relationship between depression, anxiety and burden among informal caregivers of terminally ill patients (hepatic, cardiac, renal failure)
- To improve the quality of life of caregivers of terminally ill organ failure patients

REVIEW OF LITERATURE
